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Children's Memorial Hospital
Children's Memorial Foundation
Children's Memorial Institute for
Education and Research
CM HealthCare Resources

June 17, 2002

Commissioner of Social Security
P.O. Box 17703
Baltimore, MD 21235-7703

A Member of the
Northwestern Healthcare Network

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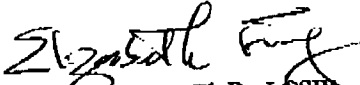
Dear Commissioner,

I wish to comment on the Social Security Administration's disability rules as they pertain to hemophilia and von Willebrand Disease. I am a social worker at Children's Memorial Hospital in Chicago, with 23 years of working knowledge and experience in working with individuals and families with bleeding disorder.

At issue within these rules are several assumptions that are not quite aligned with medical manifestations of hemophilia and vWD. Namely that all patients with hemophilia are already on prophylaxis, that breakthrough bleeds occur with a one-month gap between episodes, and that people with severe vWD be hospitalized. There also is not enough understanding of the many multiple complications and co-infections that face certain members of our community.

I am sure you will agree, it is critical that Social Security Administration's disability guidelines and rules must take into consideration all the best medical information and facts. Prophylaxis is critical to prevention; it is both cost effective and medically sound. If I can provide additional information in order to insure thoughtful Social Security rules, please let me know.

Respectfully yours,


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